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ABSTRACT

Misconceptions regarding sickle cell disease are qualitatively different among latency age patients as compared to adolescents. The evolution and resolution of these misconceptions determine the effectiveness of self-help programs for sickle cell patients. The Mount Sinai Hospital Sickle Cell Counseling Service is a coordinated center for sickle cell patients in the Hartford area and their families. A group of latency and adolescent sicklers were followed over two years with interviews and serial questionnaires. The results of the study indicate that latency age sicklers perceive themselves as chronically hospital-dependent, anticipating in-patient care with every symptom. The adolescent sickler employs denial of hospital dependency and sees himself as able to avoid in-patient care by preventative health maintenance. Issues such as body image, physical activity, sexuality, specific drugs, transfusion, peer acceptance, risk of death, and family-related guilt are found to evolve in the transition from latency to adolescence. The design of a sickle cell counseling service based on these data is presented.
(Author)

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RESOLUTION OF MISCONCEPTIONS OF LATENCY AND ADOLESCENT SICKLERS

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RESOLUTION OF MISCONCEPTIONS OF LATENCY AND ADOLESCENT SICKLERS

Continued concern of the professional and lay community in respect to Sickle Cell Disease has provided those effected with improved clinical accumen, potentially 'curative' intervention and medical-educational resources. It is interesting to note, however, that despite increased public conciousness and improved professional in-put, those effected continue to have significant misconceptions and deficiencies in knowledge of their own disorder.

In caring for individuals who have symptomatic Sickle Cell Disease, an awareness of the role and unique character of the sickler's misconceptions and their impact on his life experience would be invaluable for management by the health care team.

Clinical observations suggested qualitative differences between the perceptions of latency age and adolescent patients. This study attempts to delineate these differences and develop age appropriate strategies for intervention.

For the purpose of this study, Sickle Cell Disease is defined as a comprehensive term indicating the presence of any sickle hemoglobin within an erythrocyte. The classes within this definition provide us with a variety of nomenclature for either the clinically symptomatic or asymptomatic states.

Sickle Cell Trait is generally regarded as the asymptomatic state under normal living conditions, while Sickle Cell Anemia is equated with the infamous homozygous, symptomatic, chronic, hemolytic anemia that is the hallmark of this wide-spectrum disorder.

There also exists simultaneous heterozygosity, best denoted genotypically as Sickle Cell C-Disease and Sickle Cell β -Thalassemia. These genotypes

behave phenotypically as milder forms of Sickle Cell Anemia, however, they have the potential for a severe clinical response.

Using this nomenclature, the study sample was drawn from patients who were clinically symptomatic and involved in long-term care with the Sickle Cell Counseling Service of Mount Sinai Hospital's Department of Pediatrics in Hartford, Connecticut. Two groups of patients were selected by age criteria. Latency age sicklers represent individuals between nine (9) and thirteen (13) and numbered seven (7). Adolescent sicklers represented those between fifteen (15) and twenty (20), with a total number of ~~than~~^{ten} (10).

In order to quantitatively evaluate pre and post counseling, educational knowledge and misconceptions, a questionnaire was given to each group member prior to involvement with our Service and approximately ten (10) months to one year after counseling. The counseling sessions experienced by each subject represent a minimum of fifteen (15) hours of interaction either in group or individually. The results are tabulated and compared for presentation.

The bi-phasic design of the questionnaire allowed for evaluation of specific sickle cell disease vocabulary and misconceptions. The following slides will show pre and post counseling data for both age groups. (slide) #1

General knowledge of sickle cell disease vocabulary at the pre-counseling stage was less in the latency sickler than the adolescent, with demonstrable improvement in both groups after counseling. (slide) #2

The latency children showed a marked pre-counseling deficiency in the genetic and physiological aspects of Sickle Cell Disease, in contrast to the adolescents. There was no significant change in this perception post-counseling in the latency group as compared to the one-hundred per cent (100%) achievement for the adolescents. (slide) #3

Differentiation between the terms Sickle Cell Disease and Sickle Cell Anemia was not apparent, irrespective of age, with some improvement in perception post-counseling. (slide)#4

Growth in understanding the distinction between Sickle Cell Anemia and Sickle Cell Trait was evidenced in both latency children and adolescents after counseling. Significantly, the adolescents achieved one-hundred per cent (100%) in comparison to the latency sicklers. (slide)#5

An understanding of the broader definition of anemia prior to counseling was equally poor in both groups. Counseling which incorporated this broader definition had little effect on the perception for latency sicklers, in contrast to the increased perception in the adolescent. (slide)#6

Prior to counseling, both age groups viewed crisis in terms of the subjective experience. Later, it was perceived in terms of physiological process as well as the subjective experience. A marked change in view was noted in the adolescent group as compared to the less dramatic change in the latency group.

In the next series of slides, improved scores are equated with reduced misconceptions. (slide)#7

A high level of misconceptions is indicated by the similar, low pre-counseling scores in both groups. There is significant reduction in the number of misconceptions after counseling in both groups. (slide)#8

Questions dealing with Sickle Cell Trait reveal that the adolescents showed a greater reduction in misconceptions than the latency group. (slide)#9

Questions dealing with Sickle Cell Anemia reveal similar results. (slide)#10

Sexuality concepts indicate a growth in awareness in the adolescent to a much greater degree than exhibited by the latency sickler. (slide)#11

Vocational/educational questions represent a minimal improvement in score in the adolescent, but none in the latency group. (slide)#12

Finally, there was learning experienced about precipitating factors in both groups post-counseling with slightly greater learning by the adolescents. (slide)#13

In comparing the latency group to adolescents prior to counseling, the greatest difference lies in the knowledge of what Sickle Cell Anemia is specifically and in the differentiation between Sickle Cell Disease versus Sickle Cell Anemia versus Sickle Cell Trait. However, there is little difference in their vocabulary or their comprehension of anemia and essentially no difference in their knowledge of the crisis process. (slide)#14

The counseling experience proves to be equally effective in both groups in the areas of vocabulary and distinguishability between Sickle Cell Anemia and Sickle Cell Trait. Adolescents appear to be more receptive than latency sicklers to counseling in the areas of specific knowledge(that is, physiological process) about Sickle Cell Anemia, distinguishability between Sickle Cell Anemia versus Sickle Cell Disease, anemia in its broadest sense and the crisis process. Whether the difference in receptiveness and learning is a developmental or pedagogical problem is not certain. In the latency group the lesser degree of distinction exhibited between Sickle Cell Disease versus Sickle Cell Anemia in comparison to the adolescents, may be due to the fact that to the latency child there is no threat to the phrase Sickle Cell Disease. To the adolescent "disease" represents an active process and "anemia" a passive one. It would appear that the latency child either denies or does not perceive the 'threat' of disease versus anemia and that the adolescent wishes to insulate himself by making the distinction.

Qualitatively, in both groups the ease of entry into the health care system with acute illness was improved post-counseling through more effective communication with health professionals.

The adolescents' ability to perceive crisis in a more objective sense than the latency child may reflect the maturation process and beginning foundation for adult coping mechanisms.

The ability of the adolescent to show greater reduction in misconceptions about Sickle Cell Trait and Sickle Cell Anemia as compared to the latency group, can be attributed to his greater comprehension of complex issues.

Sexuality is of greater importance to the adolescent sickler in respect to both self-image and family planning. Normal developmental fears and anxieties are compounded by the presence of their disorder and the perceived limits of life span.

The absence of significant learning in the area of vocational/educational matters is not surprising amongst latency sicklers who do not perceive themselves in the world of work, however, the adolescent sicklers also appear to have limited perceptions of themselves in the world of work. This may be realistic and reinforced by those in their environment.

Irrespective of age, counseling was beneficial in reducing over-all misconceptions.

The differences noted between the latency and adolescent sicklers should be viewed as a function of achieved psycho-social development. It must be recognized that Sickle Cell Disease, as any chronic illness, may delay psycho-social development. This awareness of the role and unique character of the sickler's misconceptions can be an invaluable tool for age-specific strategies of the health care team.

TABLE A (#1)

SPECIFIC SICKLE CELL VOCABULARY		
COUNSELING	LATENCY	ADOLESCENT
PRE	34.4%	51.3%
POST	87.3%	91.16%

TABLE B (#2)

SICKLE CELL ANEMIA DEFINITION		
COUNSELING	LATENCY	ADOLESCENT
PRE	28.5%	75%
POST	57.1%	100%

TABLE C (#3)

SICKLE CELL ANEMIA v/s SICKLE CELL DISEASE		
COUNSELING	LATENCY	ADOLESCENT
PRE	0%	25%
POST	14.2%	50%

TABLE D (#4)

SICKLE CELL ANEMIA v/s SICKLE CELL TRAIT		
COUNSELING	LATENCY	ADOLESCENT
PRE	42.8%	67.5%
POST	85.7%	100%

TABLE E (#5)

ANEMIA DEFINITION		
COUNSELING	LATENCY	ADOLESCENT
PRE	14.2%	25%
POST	57.1%	87.5%

TABLE F (#6)

SICKLE CELL CRISIS DEFINITION		
COUNSELING	LATENCY	ADOLESCENT
PRE	14.2%	12.5%
POST	57.1%	87.5%

TABLE G (#7)

TOTAL QUESTIONS % CORRECT		
COUNSELING	LATENCY	ADOLESCENT
PRE	11%	8.8%
POST	35.5%	46.6%

TABLE K (#8)

SICKLE CELL TRAIT % CORRECT		
COUNSELING	LATENCY	ADOLESCENT
PRE	13.6%	17.6%
POST	36.4%	45.5%

TABLE L (#9)

SICKLE CELL ANEMIA % CORRECT		
COUNSELING	LATENCY	ADOLESCENT
PRE	13%	43.2%
POST	35%	52.2%

TABLE H (#10)

SEXUALITY % CORRECT		
COUNSELING	LATENCY	ADOLESCENT
PRE	12.5%	12.5%
POST	25%	50%

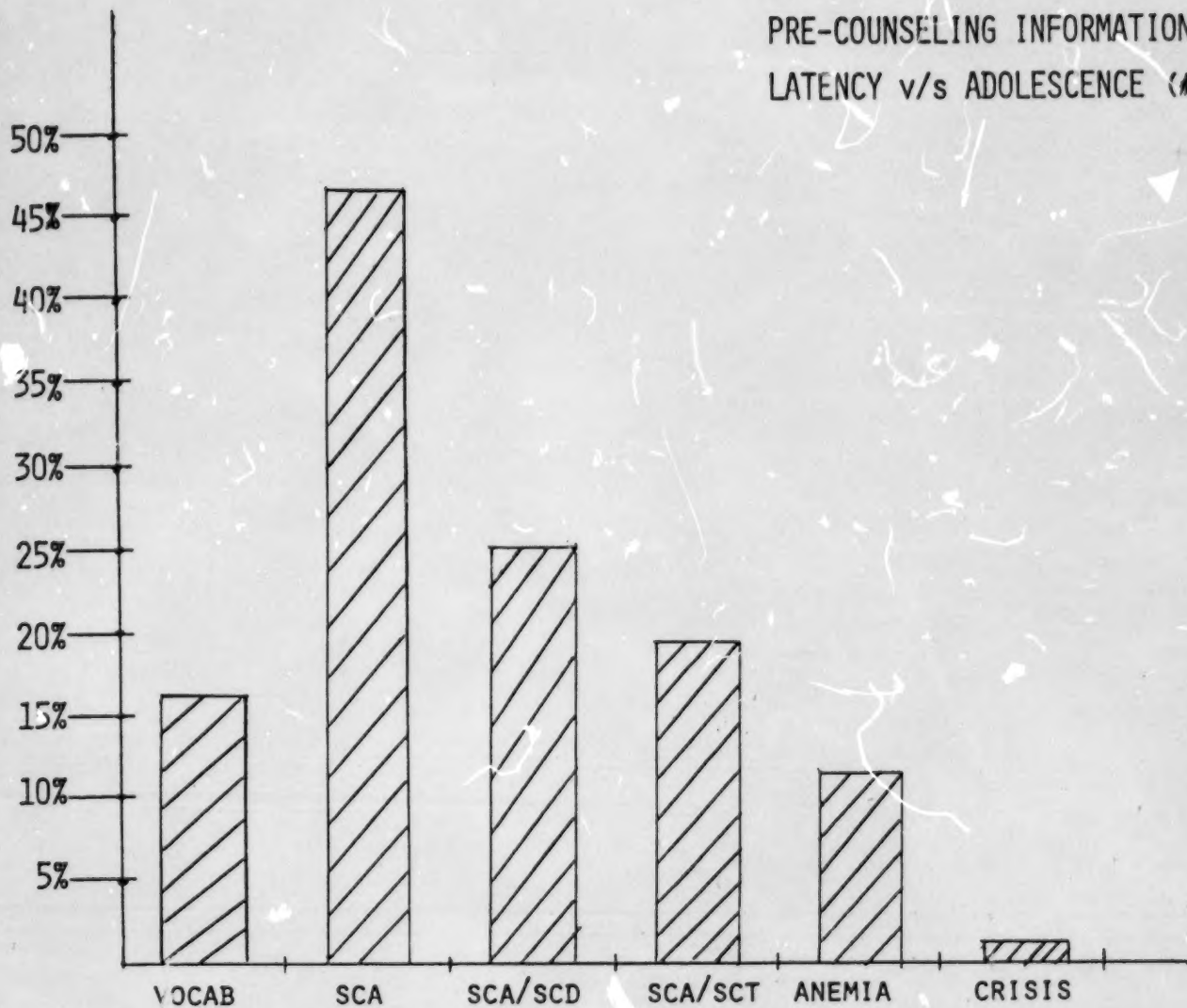
TABLE I (#11)

VOCATIONAL/EDUCATIONAL % CORRECT		
COUNSELING	LATENCY	ADOLESCENT
PPE	33.3%	0%
POST	33.3%	33.3%

TABLE J (#12)

PRECIPITATING FACTORS % CORRECT		
COUNSELING	LATENCY	ADOLESCENT
PRE	10.5%	10.5%
POST	39.5%	47.3%

PRE-COUNSELING INFORMATION
LATENCY v/s ADOLESCENCE (#13)



POST COUNSELING INFORMATION
LATENCY v/s ADOLESCENCE (#14)

